

TRANSITION TO ADULT HEALTH CARE

#1: Best Practice Guidelines

The Best Journey to Adult Life for Youth with Disabilities: An Evidence-based Model and Best Practice Guidelines for the Transition to Adulthood for Youth with Disabilities.

Debra Stewart, Matt Freeman, Mary Law, Helen Healy, Jan Burke-Gaffney, Mary Forhan, Nancy Young, & Susan Guenther, 2009. Published and distributed by CanChild Centre for Childhood Disability Research

These are generic guidelines which can be used and adapted by different communities and services. For more information see:

<http://transitions.canchild.ca/en/OurResearch/bestpractices.asp>

#2: Transition to Adulthood Issues for Children Who Have Had Transplantations

[Annunziato RA](#), [Shemesh E](#). "Tackling the spectrum of transition: what can be done in pediatric settings?" [Pediatr Transplant](#). 2010 Nov;14(7):820-2. doi: 10.1111/j.1399-3046.2010.01404.x.

#3: Transition to Adulthood Issues for Individuals with Congenital Heart Problems

[Alison Knauth Meadows](#), [Valerie Bosco](#), [Elizabeth Tong](#), [Susan Fernandes](#) and [Arwa Saidi](#).

“Transition and transfer from pediatric to adult care of young adults with complex congenital heart disease,” [Current Cardiology Reports](#). 2009, [Volume 11, Number 4](#), 291-297, DOI: 10.1007/s11886-009-0042-8

#4: A brief video about the transition program at Nationwide Children’s Hospital (Columbus, Ohio) for youth with congenital heart disease can be found at:

http://www.youtube.com/watch?v=T-j9Bd_dAfE

#5: Transition to Adulthood Issues for Individuals with Diabetes

[Gee L](#), [Smith TL](#), [Solomon M](#), [Quinn MT](#), [Lipton RB](#).. “The clinical, psychosocial, and socioeconomic concerns of urban youth living with diabetes,” [Public Health Nurs](#). 2007 Jul-Aug; 24(4):318-28.

#6: Transition to Adulthood Issues for Individuals with Arthritis

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Scal Peter, Horvath Keith, Garwick Ann. "Preparing for Adulthood: Health Care Transition Counseling for Youth With Arthritis," *Arthritis & Rheumatism (Arthritis Care & Research)*. January 15, 2009, Vol. 61, No. 1, pp 52-57.

#7: Transition to Adulthood Issues for Individuals with Developmental and Behavioral Disorders

Palfrey JS, Foley SM, Sharma N, "Developmental and Behavioral Disorders Grown Up, " *Journal of Developmental & Behavioral Pediatrics*. December 2008, Vol. 29, No. 6, pp 524-33.

#8: Transition to Adulthood Issues for Individuals with Inflammatory Bowel Disease

Hait EJ, Barendse RM, Arnold JH, Valim C, Sands BE, Korzenik JR, Fishman LN. "Transition of Adolescents With Inflammatory Bowel Disease From Pediatric to Adult Care: A Survey of Adult Gastroenterologists, " *Journal of Pediatric Gastroenterology and Nutrition*. 2008, 48:61-65.

#9: Transition to Adulthood Issues for Individuals with Cystic Fibrosis

McLaughlin SE, Diener-West M, Indurkha A, et al. "Improving transition from pediatric to adult cystic fibrosis care: lessons from a national survey of current practices," *Pediatrics*. 2008, 121:e160-6.

#10: Transition to Adulthood Issues for Individuals with Cerebral Palsy

Wiegerink DJ, Roebroek ME, Donkervoort M, et al. "Social, intimate and sexual relationships of adolescents with cerebral palsy compared with able-bodied age-mates," *J Rehabil Med*. 2008;40(2): 112-8.

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#11: Helpful articles for professionals caring for young adults with special health care needs with these being suggested by Dr. Janet E. McDonagh, Clinical Senior Lecturer in Pediatric and Adolescent Rheumatology at Birmingham Children's Hospital, Birmingham, United Kingdom:

Lostein DS, Inkelas M, Hays RD, Halfon N, Brook. "Access to care for youth with special health care needs in the transition to adulthood," J Adol Health. 2008;43:23-29.

Park MJ, Irwin CT. "Youth with special health care needs: facilitating a healthy transition to young adulthood," J Adol Health. 2008;43:6-7.

Committee on Adolescence. "Achieving Quality Health Services for Adolescents," Pediatrics. 2008;121:1263-1270. <http://aapolicy.aapublications.org/cgi/reprint/pediatrics;121/6/1263.pdf>

Dr. McDonagh also suggested articles #9 and #10 listed previously

#12: Article regarding where children with chronic illness go for health care as adults:

Steinbeck KS , Brodie-L, , Towns SJ. "Transition in chronic illness: Who is going where?" J of Paediatrics and Child Health. Article first published online: 19 AUG 2008

DOI: 10.1111/j.1440-1754.2008.01321.x

#13: Identified Needs of Physicians and Patients for Improved Transition to Adult Health Care

Peter NG, Forke CM, Ginsburg KR, Schwarz DF. "Transition From Pediatric to Adult Care: Internists' Perspectives," Pediatrics. 2009, Vol. 123, pp 417-423.

#14: Oct. 2008 Article from National Alliance to Advance Adolescent Health Care:

"Pediatric Perspectives and Practices on Transitioning Adolescents with Special Needs to Adult Health Care," can be located by going to

<http://thenationalalliance.org/publications/index.cfm?topicID=3>

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#15: Useful resources from the Transition Treatment Team at the Hospital for Sick Children in Toronto, Canada:

<http://www.sickkids.on.ca/myhealthpassport/>

once on that website, health passport can be obtained

<http://www.sickkids.ca/good2go/>

once on that website, click “Transition Intervention Menu” to find readiness checklists, easy interventions, clinical pathways, graduation, graduation letter, facilitation of first adult appointment, special transition clinics, and materials for families

#16: A good practice guide on effective transition from children's to adult services for young people with complex health need published by the Department of Health and the Department for Schools, Children and Families: in the United Kingdom:

Transition: moving on well can be down loaded for free at

<http://www.dh.gov.uk/en/Publicationsandstatistics/index.htm>

once on that website, click “order publications for free online” to the right, then put in publication title

#17: Helpful health-related training materials that can be used with schools, health providers, families, and directly with youth having disabilities to help those youth learn to more effectively manage their health care concerns (developed by The Wisconsin Community on Transition Health Practice Group):

Health and the IEP, Transition to Adult Health Care: A Training Guide in Three Parts-2nd Edition, The Workbook for Youth, My Health Pocket Guide, The Transition to Adult Health Care Checklist: Preparing for Life as an Adult can all be downloaded for free at

<http://www.waisman.wisc.edu/wrc/pub.html>

#18: Example of a children’s hospital’s transitional care policy:

http://www.chw.edu.au/prof/gps/transitional_care_policy.pdf

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#19: Example of how Florida Health Care Transition Services Task Force for Youth and Young Adults with Disabilities took Florida Legislature's Senate Bill 988 mandate to issue a report and set of recommendations for assuring successful transition from pediatric to adult care, completed the report in December 2008, and continues work group activities to implement task force recommendations to ensure successful transition.

Tools and other transition aids developed through the group's activities can be found at:

<http://www.floridahats.org/>
<http://hctransitions.ichp.ufl.edu/digest.php>
<http://hctransitions.ichp.ufl.edu/>

#20: Many national, state, local support groups for specific conditions causing chronic illness and disabilities have guides for transition to adulthood planning on their websites. Most guides can be found by going to the homepage of the group then clicking "Transition to Adulthood" or a similar topic on that homepage or by putting in "Transition to Adulthood" on the search device offered on the group's homepage. Below are examples of such guides from the Autism Speaks, National Fragile X Foundation, Spina Bifida Association, and Chron's and Colitis Foundation of America. websites. (Many support groups have information regarding health insurance for adults with the specific condition supported by the group.)

<http://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit>

<http://www.fragilex.org/html/planning.htm>

<http://www.sbp Preparations.org/>

<http://www.ccfa.org/living/?LMI=1>

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